

# Inside the black box of shared decision making: distinguishing between the process of involvement and who makes the decision

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## Abstract

**Background** Shared decision making has practical implications for everyday health care. However, it stems from largely theoretical frameworks and is not widely implemented in routine practice.

**Aims** We undertook an empirical study to inform understanding of shared decision making and how it can be operationalized more widely.

**Method** The study involved patients visiting UK general practitioners already well experienced in shared decision making. After these consultations, semi-structured telephone interviews were conducted and analysed using the constant comparative method of content analysis.

**Results** All patients described at least some components of shared decision making but half appeared to perceive the decision as shared and half as 'patient-led'. However, patients exhibited some uncertainty about who had made the decision, reflecting different meanings of decision making from those described in the literature. A distinction is indicated between the process of involvement (option portrayal, exchange of information and exploring preferences for who makes the decision) and the actual decisional responsibility (who makes the decision). The process of involvement appeared to deliver benefits for patients, not the action of making the decision. Preferences for decisional responsibility varied during some consultations, generating unsatisfactory interactions when actual decisional responsibility did not align with patient preferences at that stage of a consultation. However, when conducted well, shared decision making enhanced reported satisfaction, understanding and confidence in the decisions.

**Conclusions** Practitioners can focus more on the process of involving patients in decision making rather than attaching importance to who actually makes the decision. They also need to be aware of the potential for changing patient preferences for decisional responsibility during a consultation and address non-alignment of patient preferences with the actual model of decision making if this occurs.

## Introduction

Shared decision making was first characterized as requiring the co-operation of at least two parties – the clinician and the patient and others, that both parties take steps to participate in the process of treatment decision making, that this involves information sharing as a prerequisite to sharing decision making, and then that a treatment decision (which may be to do nothing) is made, and both parties agree to the decision.<sup>1</sup> However, it stems from largely theoretical frameworks and ethical considerations. It is widely advocated in policy terms but is not widely implemented in routine practice.<sup>2,3</sup> Further empirical studies are needed to explore this apparent gap between theory and policy and routine practice.

Gafni *et al.* described a spectrum of decision-making *agency*, with a spectrum between ‘physician as perfect agent’ and the truly informed consumer.<sup>4</sup> Physicians can act as perfect agents if they are fully aware of the patient’s values, preferences, opinions and goals, and can then combine this with their clinical knowledge or experience to choose the ‘best’ option. The consumer can make an informed choice if they have sufficient clinical knowledge and then combine this with their values, preferences and goals. As neither party is fully able to derive and use the knowledge and experience or personal values and goals of the other, shared decision making offered a possible middle ground with each party contributing to a decision.

Ensuing research on shared decision making explored the specific elements of consultations (the ‘competences’) and how these can be taught and assessed.<sup>5,6</sup> This focus may have detracted from attention to the more global nature of the consultation and the clinician–patient relationship itself.<sup>7</sup> There has been research focusing on who made the decision. Scales covering the spectrum from ‘paternalism’ through ‘shared’ to ‘informed choice’ models have been developed,<sup>8</sup> but sometimes found to be problematic in terms of how patients ascribe locus of decision making for what happened.<sup>9</sup> Patient reports may conflict when interview data and answers to structured questions on the decision are compared. Perhaps

there are uncertainties about the meanings of terms embedded in such questions. Alternatively, this may be that this not a particular area of interest for patients, who may be more concerned with other aspects of the decision-making process such as time taken, feeling listened to and respected.<sup>10</sup>

Other patient-based outcomes of decision making have been evaluated, often categorized as cognitive, affective or behavioural outcomes.<sup>11</sup> Shared decision-making approaches can achieve a range of health care and health benefits.<sup>12–14</sup> Clinicians and patients also generally indicate positive responses to sharing decisions.<sup>15,16</sup>

However, despite accumulating evidence and policy support, shared decision making is only sparsely implemented in routine practice.<sup>3,17,18</sup> Barriers to widespread implementation include time pressures, incentives to hit targets for payment, unwillingness to share power, difficulties expressing uncertainty, managing conflicting information sources and the absence of risk communication aids.<sup>3,17,19–22</sup> Medical training has also proved slow to adapt to the patient-centred approach and continues to concentrate on understanding disease and treatment, without offering similar insight into the understanding of patients.<sup>23</sup> Shared decision making probably requires attitudinal shifts by clinicians as well as the conventional communication skills currently taught within medical education.<sup>24</sup> It may also not be appropriate in all situations.<sup>25</sup> Some – those characterized by higher stakes or more limited options – may be more suited to an ‘informed consent’ approach (also termed ‘assumed engagement’<sup>7</sup> than a shared decision-making approach.<sup>26</sup> Overall, these contextual issues encourage persistence of the paternalistic model of consulting.<sup>3</sup>

However, the importance of these potential barriers is not fully understood. Further barriers or different interpretations of what it means to ‘share decision making’ could also be identified. Potentially, a deeper understanding of the concepts, values, goals, processes and elements of shared decision-making stages could be gained from visiting these issues with patients or clinicians to explore what they bring, experience and

take away from consultations. Few empirical studies have examined shared decision making in depth in routine clinical practice to examine whether the concepts for patients and clinicians are as they are proposed in the literature. Currently there are variations in the conceptualization of shared decision making and its characteristics and core elements.<sup>27</sup> Deepening or developing the current understanding may assist in re-directing efforts to promote shared decision making in practice, to bridge the gap currently found between theory and practice.

We undertook an examination of shared decision making in practice, using interviews with patients after consultations with a general practitioner experienced in the approach. Their experience derived from prior participation in a trial of shared decision making and risk communication training,<sup>28</sup> involving considerable commitment and deep learning.<sup>16</sup> As a follow-up study, these doctors continued to apply shared decision-making approaches, and audio-recorded (after patient consent) selected new consultations for analysis. We interviewed these patients about their experiences and views, aiming to explore patients':

- attribution of the locus of decision making within the consultation;
- reported experience of the process of decision making; and
- reported benefits or adverse outcomes experienced from participating in a shared decision-making consultation as part of normal contact with their general practitioner.

From this we sought to integrate these findings towards an empirically based understanding of shared decision making, and to try to draw out the lessons for education, clinician training and wider promotion of shared decision making in policy initiatives.

## Method

### Context

General practitioners already trained in shared decision-making techniques over a 6-month

period<sup>28</sup> were invited to continue in this follow-up study. Participating doctors audio-taped up to 10 consultations with patients presenting for the first time with one of the following conditions: hypertension, cholesterol, menorrhagia, hormone replacement therapy, prostatism, atrial fibrillation, contraception and antibiotics for upper respiratory tract infections. Patients consented to audio-taping and subsequent telephone interview about the communication issues in their consultation.

### Sample of patients for post-consultation interviews

From the original group of 20 doctors, 12 volunteered for this phase of the study, of whom eight actually recruited patients, recruiting 68 patients in all to the study. The consultation audio tapes were assessed for shared decision making by two experienced researchers using the OPTION scale.<sup>29</sup> As these consultations were selected by skilled clinicians for their potential application of shared decision making, all consultations were retained in the sample, even if the OPTION score indicated little patient involvement in decision making. It was felt these 'anomalous' cases would be as informative as the 'ideal' cases of shared decision making. Following these 68 consultations, 61 taped post-consultation interviews were obtained.

### Sample of interviews for analysis

From these 61 study consultations, a purposive sampling frame was used, ensuring each doctor was represented at least once and each condition at least twice in the final sample. Sampling by condition ensured that a range of ages and each gender were represented among the interviewees, as these have been postulated as potentially important determinants of patient preference for shared decision-making approaches.<sup>30</sup> This resulted in 17 interviews for analysis (Table 1).

Interviews were conducted as soon after the consultation as possible, at a median of 3 days and no longer than 28 days afterwards. These interviews were semi-structured, lasted approxi-

**Table 1** Achieved data set and sub set of interviews sampled by condition and doctor ID

Condition	Consultation totals	Interview totals	Sampled interviews by Doctor IDs
Protatism	12	12	29, 55
Atrial fibrillation	2	2	22, 54
Menorrhagia	8	7	25, 43
Hypertension	8	7	25, 43
Cholesterol (IHD)	9	8	1, 43, 47
Contraception	2	2	22, 54
Menopausal symptoms	22	18	25, 43
Otitis media	5	5	1, 54
Total	68	61	17

**Box 1** Outline structure, with areas for probing, in telephone interview after study consultation

Agreeing the nature of the condition or decision
Reflections on the consultation
Perceptions about whether options existed
Feelings about being involved in decisions
Perceptions of involvement in decision
Who the patient felt had made the main decision in the consultation: extent of responsibility lying with patient or doctor
Explored uncertainties about this if relevant
Whether the doctor might agree with this assessment of who made the decision
Opinion about information provided
Amount; detail; format; understandable; usefulness
Other sources of information available and used by patient
People to discuss this with
Outcomes of the consultation
Treatments, tests, referrals
Plan to review decision in future
Certainty about having chosen the best option
Confidence to adhere to chosen plan
Patient's priorities for health and health care episode
Patient's perceptions of doctor's priorities for health and health care episode
Degree of match/mismatch between these, and patient's views on this
Views on 'doctor-patient partnership' or other collaboration
Confidence to approach doctor about an issue or to review
Perceived differences between this consultation and previous experiences
With this or different doctors

mately 30 min, explored themes as outlined in Box 1, and were transcribed verbatim from audio tapes for analysis.

## Analysis

The 17 interview transcripts were analysed by content analysis.<sup>31,32</sup> After a period of familiarization and immersion in the transcripts a coding structure was developed and then applied, using the constant comparative method, by AE and another researcher (JK) independently. Coded transcripts were retained for audit. Interviews were mapped on a grid according to their coded characteristics and consistencies and exceptions between the interviews identified and explored. Emergent themes by which shared decision making could be conceptualized and understood were identified from these codes and agreed in discussion between the authors and researcher (JK) after re-reading of transcripts. Codes were then categorized under these themes in the data by AE and JK.

## Results

The mean OPTION score for the 17 purposively selected consultations was 62.8 (median 65, range 42–78), indicating a high level of patient involvement in decisions about their treatments.<sup>29</sup> The 17 post-consultation interviews were analysed and data examined for themes. We present first an initial overview, then selected data illustrating the themes identified, and then synthesize them for their concepts, implications and lessons for clinical practice. The themes are as follows:

### 1 Control and power

- (a) Locus of decision making in a 'shared decision-making' consultation
  - (i) difficulty in deciding who made the decision
  - (ii) indications of different meanings of 'sharing decisions'

### (b) Construction of control

### 2 Experiential reflections on the process

- (a) novel experience of knowledge and understanding
- (b) novelty of involvement
- (c) time constraints
- (d) uncertainty over validity of 'doing nothing' as a choice
- (e) doctor as a trusted source of information

**Table 2** Patients' perceived locus of control in treatment decisions

Patient ID no.	Perceived locus of decision making: 'informed consent', 'shared' or 'sole' (patient-led, 'informed choice')*	Interview excerpts
103	Informed consent	I think once Dr C showed me the figures I could work it out for myself. I agreed with the specialist and Dr C
22	Shared	He's done his best in giving me the information... I think it was a shared decision
45	Shared	I think I would probably say shared. But only by 51/49!
62	Shared	Oh, very shared... I think it was a joint decision
98	Shared	Very much shared... I do feel that his input helped me to come to the right conclusion about the treatment for me
100	Shared	I think it was a shared decision...
109	Shared	A shared decision... We went through all the charts... and I was able to choose the best sort of thing for me
107	Shared	I suppose it was a joint decision if I asked him
1001	Shared	I think it must be shared...
8	Sole	Well it was me ultimately... I was trying to read whether she wanted me to take it or whether she thought I was daft... I didn't get that feeling
15	Sole	But at the end of it all, she left it, it was my decision
18	Sole	It was all my own decision
65	Sole	I think really I said that I would prefer to wait
86	Sole	I think I decided
87	Sole	I'd say it was my decision
41	Sole	He explained the issues and then sort of handed it over to me really...
111	Sole	It was me who made the choice

\*Perceived locus of decision making assessed independently by two researchers (AE, JK), according to models from Charles *et al.*<sup>1</sup> and Whitney<sup>26</sup> and then discussed to achieve consensus.

### 3 Experienced outcomes

- (a) patient satisfaction with information sharing not decision locus of control
- (b) when a shared decision is not a good outcome for the patient

#### Overview

The interviews with patients suggested two distinct types of consultations had occurred. Some interviewees felt clearly that they had made or led the decision, thus perhaps fitting the 'informed choice' model,<sup>1</sup> whereas an equal number believed they had made a shared decision with their doctors. One interviewee (ID 103, Table 2) felt he had agreed with the recommended treatment in the light of information presented – seemingly the 'informed consent' model.<sup>26</sup> All except for two patients expressed

satisfaction with both their doctor and the consultation. Patients described positive features of the decision-making process, including greater understanding, resolving uncertainty about possible interventions, and how patients looked to their doctors as trusted sources of information and advice. Some interviewees described changing preferences for making the decision ('decisional responsibility') during consultations, and how a doctor's failure to match the actual decision-making model with such preferences during the consultation can be problematic.

#### *Locus of decision making in a 'shared decision-making' consultation*

Not all patients described the decision as shared. Approximately half perceived that the decision had been their own, describing an 'informed choice' position in which the doctor had

provided them with information and allowed them to decide. Patients appeared to have experienced this as choosing between the presented options. For one patient the decision was to defer an actual decision about treatments. Patients' statements about who made the treatment decisions in their consultations are shown in Table 2.

However, the categorizations of who made decisions may be over-simplified. The following sub-themes illustrate that patients had often not considered these issues before, and that the meanings attributed to 'shared decision making' by patients may be different to those represented in the literature.

#### *Difficulty in deciding who made the decision*

Patients appeared to have some difficulty in deciding who had made the decision. Their statements were frequently qualified by 'I think...' and 'I suppose...' and several patients justified it by sharing their reasoning. A smaller number of patients, though, could immediately assert that the decision was '*very much shared*' (I98) or '*Oh, no, no, absolutely mine*'. (I15)

#### *Indications of different meanings of 'sharing decisions'*

There were indications that the meaning of shared decision making was different for different patients. Consider the similarity between these two interviewees, each following a consultation about contraception, in their descriptions of how they reached the point at which a decision could be made about treatment:

I18: Well, Dr C. said which one is most effective...and she gave me a chart and we looked at the chart together and ... then I said I wouldn't mind the second most effective one, 'I'll try this one', so my decision entirely.

I109: We went through all the charts, the success rates and the failure rates of all the different types of contraception and then I was able to choose the best sort of thing for me. So that was good.

R: ...who made the decision...?

I109: A shared decision.

Interviewees 18 and 109 both describe the process of comparing risks and benefits of

different treatment options, when offered this information by their doctor. From a theoretical perspective it appears that they are describing an informed choice model. However, one interviewee (I109) reaches a quite different conclusion about who made the decision, describing it as 'shared'. Whilst the interviewee offers no further explanations, this suggests that the meaning of 'shared' for this patient is quite different to usual interpretations (and described in the literature).<sup>27</sup> This 'deviant' case raises the possibility that if patients' understandings may be variable, then patients and clinicians can sometimes be at cross-purposes. This needs to be explored with patients if it is to be resolved and to avoid hindrances to shared decision making for at least some patients.

#### *Construction of control*

Patients displayed a high degree of consistency in the way they used language concerning their attributions of locus of decision making. Shared decision makers referred to their doctor and themselves as 'we' and described joint responsibility for their chosen course of action:

I45: We were going to wait and see what the blood test said and see what happens ... we decided to stay where we are. We are going to actively do nothing.

Those who described the decision as their own characteristically used 'I' relating to the decision making and 'he' or 'she' when referring to the doctor's contribution:

I86: Whenever he came to a critical point, he asked my opinion, what I thought of it... I thought it was very good...He had all the information to hand ready for when I went into the consultation.

This interviewee takes a distinctly different position from I45. They appear to describe a healthcare provider-consumer relationship in which the doctor is offering them choices. The 'I' is invested with the power of choice, the 'he' of the doctor is relegated to delivering a service. The traditional power asymmetry of the paternalistic model, with power resting with the professional, is reversed.<sup>33,34</sup> Another patient was even clearer where the initiative lay:

I65: I wanted information on it, but then said 'well, thanks very much, but I'd like to think about it,' ... I suppose I did take the initiative and say 'thank you, but – (laughs) – no thank you!'

The interview data suggested that the 'shared decision-making consultation' delivers not only shared, but also 'informed choice' decisions from the patients' perspective. This difference appeared more related to patient characteristics than the conditions, including for example people's reasoning processes, but other influences were not yet clear. There were also indications about the dynamic nature of the process, and the game-playing or the 'dance' being acted out:<sup>35</sup>

I45: It was my decision but it was a guided decision.

F: Whose decision do you think the doctor would think it was?

I45: I suspect he might say it was 51/49 led – by him.

F:(laughs) Right OK.

I45: And if so that would be because my psychology was right - you've got to let him think he's winning but he isn't.

### *Experiential reflections on the process*

#### *The novel experience of gaining knowledge and understanding*

A prominent theme in the interviews was the unusual experience for patients of understanding treatments more fully. One patient describes being corrected on mistaken assumptions, and how new knowledge was a welcome surprise:

I18: I was surprised ... she put me straight on some of the things that I thought that I had already known, so she clarified it a bit more.

Several patients described their consultations as a departure from usual experience, for example:

I109: I didn't come away like I have often done...thinking, Oh, what was that all about?

Patients appreciated that their doctors were showing sensitivity to their individual needs for information and were aware their doctor was working with them:

I87: He was saying it in the words you would understand, so he wasn't using big words ... I can't fault him for that.

#### *The novelty of involvement*

As well as the novelty of information and understanding, interviewees also noted the novelty of being made aware about treatment options, and the consequent sense of involvement in the process.

I 103: That's the first time I've been involved in a life threatening, or non-life threatening situation in terms of the medical decision.

Interviewees were aware that they would need to build up their confidence and abilities to engage effectively in the process.

#### *Time constraints*

These consultations were part of routine clinics and did not have extra time scheduled but patients reported longer consultations than usual. Many patients noted it was unusual, even 'extraordinary', to have time to discuss treatment options fully:

I18: I had lots of time and it was more understandable. I can remember sort of more how it went. Usually if I see the doctor I didn't tell them half what I wanted, and I forget what the doctor told me because I'm rushing it but here I felt it all went fine.

Although valued by patients, time factors were also important to patients, suggesting that the promotion of shared decision making may also depend on managing patients' expectations that consultations will take longer.

I1001: it was a much more interesting and longer consultation than previous ones ...

I would have wanted to know beforehand. It pushed the schedule out of the day a bit being in there all that extra time.

#### *Patients' uncertainty over validity of 'doing nothing' as a choice*

In describing how they felt about the consultation, interviewees highlighted a need for reassurance, especially when 'doing nothing' was their preferred course of action. Patients

described their willingness to comply with their doctors' wishes whilst asserting a preference to 'do nothing' if this were legitimate. But there appeared to be uncertainty that this could be legitimate or even permitted:

I8: I'm quite pleased to be, umm, given the opportunity to at least question the necessity to have a drug like that.

This interviewee (I8) and another (I65) also described a belief that their doctor would step in if they thought she was making a poor decision, and this belief enables her not to take medication:

I65: I think she seemed quite happy with a number of my decisions so, if her ideas hadn't coincided ... I would have hoped that she would say 'well look I think you really ought to do this'.

#### *Doctor as a trusted source of information*

Hand in hand with the patients' experience of being fully informed was their stated preference for information from their doctor as their most trusted source of information relating to their health. Several interviewees reported that they gather information from a number of sources including the Internet, but indicated how they would take this information to their doctor for further clarification, though aware of the potential for bias also:

I109: I've seen figures from other sources, you know magazines and stuff like that, but I've never actually been shown it and gone through it with a doctor. So that was really good.

#### *Experienced outcomes*

##### *Satisfaction with information sharing, not dependent on decision locus of control*

Most interviewees were satisfied with their earlier consultation, whether they believed they had made a shared decision, or made the decision themselves, and for the 'informed consent' case. Satisfaction frequently stemmed from their doctor's reported commitment to sharing information as a distinctive feature of their practice. Patients valued doctors who are 'straightforward', 'fair' and 'explain it carefully':

I111: She's a bit different to the usual doctor ... I never think about seeing anybody else.

I62: Dr W explains everything very well. She doesn't just sort of ride over the top of things, she talks to me ... I find her very straightforward... If she's got any thoughts she shares them, and I feel much happier about that.

Whilst satisfaction appeared consistently related to information sharing, some patients also described their satisfaction in relation to the process of shared decision making:

I111: 'I felt very involved... she didn't just say, 'Oh well, take more of these pills'... so she was involving, yes.

These positive outcomes for patients, relating to information sharing and sometimes involvement in decisions indicated the value of these 'shared decision-making consultations' to these patients. However, other data indicated this was not always the outcome.

##### *Dissatisfied patients: changing preferences for involvement and 'non-alignment'*

Two patients were generally negative about their consultation, in each case after a shared decision with their doctor. The first patient had unmet expectations (I1001). Rather than getting a prescription before going on holiday, he was engaged in an unwanted discussion of risks and benefits about treatments. The second patient initially seemed comfortable with the process of involvement in decisions but later in the interview indicated she was looking to the doctor for an answer. Initially she appeared to indicate a preference for informed choice, then for shared decision making, and finally for a paternalistic decision. At times she appeared comfortable, but at others it was clearly not concordant with her preferences for decisional responsibility and involvement in decision making.

I22: Well I said to the doctor, as long as the decision is informed professionally, my choice, that's all they can do really.

I22: We talked about the risks of... cardiovascular and then breast cancer in particular and he did ask me whether I would, or how would I feel about making my own decision, and obviously I feel it has to be in collaboration with him really.

I22: I mean he didn't say 'you definitely must take this' and he did ask whether I would be involved in making the decision and I said as long as I have the information from him, or a professional person... but I suppose I would so like somebody to sit down and say yes, you will have this, you could have this, you could have that, but he doesn't actually do that.

It was not clear whether the patient felt she did receive sufficient information to make the decision, but it seems to identify how preference for decisional responsibility was a changing feature of the consultation. Another interviewee also seemed to indicate that she would have preferred a more significant lead and support from the doctor than she perceived:

I87: Dr H. did say do you want me to make the decision? I think he's got his own ideas but he didn't commit to anything, no.

This dynamic variation identified by reflection on (within) a single consultation suggests that doctors need to be aware of this potential for rapid change, and to continually check whether their approach is *aligned* with the patient's desired level of decisional responsibility at repeated intervals during a consultation.

### Integrating themes

Interviewees seemed to place more value on the process of involvement in sharing decisions than on who had made the decision. The information sharing stages appeared particularly valued, with the opportunity for deepening knowledge and understanding. Knowledge and understanding, particularly regarding the legitimacy of different options, including 'doing nothing', seemed almost automatically to make people more involved, either in a shared or an informed choice model. However, several uncertainties could hinder this happening. These included the novelty of the process, and having to learn information gathering and engagement in decision making. Doctors seemed a trusted source of information, particularly perhaps to digest a range of sources and identify the most useful information to support decision making.

As well as uncertainties, there were a number of barriers to implementing shared decision making. Time constraints were described – but here from the patient's perspective not the clinician's. *Alignment* between the patient's preference for decisional responsibility making and the actual approach adopted by the doctor seemed important, and had been problematic in some instances. Preferences for this responsibility appeared to have been dynamic, and doctors needed to recognize or match the model of decision making *at each stage of the consultation* to the preferences or needs of the patient for the consultation to be successful.

## Discussion

### Principal findings

In consultations selected as suitable for shared decision making, patients perceived the actual decision as being patient-led (consistent with 'informed choice' model<sup>1</sup> in as many consultations as those they perceived it as shared. However, patients exhibited uncertainty about who had made the decision, reflecting firstly some different meanings attached to the concept of decision making from those in the literature, and secondly that preferences for decisional responsibility vary during a consultation. As they vary dynamically, there is potential for unsatisfactory interactions, which may be realized if the adopted decision-making model does not align with patient preferences at that stage of a consultation. However, if a shared decision-making consultation is conducted well, overcoming barriers of time, possible low expectations or lack of knowledge of available options, then the process is valued by patients, and effective in terms of satisfaction, understanding and confidence in the decisions made. A distinction is suggested between the process of involvement (option portrayal, exchange of information, and exploring preferences for who makes the decision and when) and the actual decisional responsibility (who makes the decision).

### Strengths and limitations of this study

This study offers insights into patients' experiences of shared decision-making consultations, in the context of UK general practice. The OPTION ratings of these consultations confirmed that shared decision-making approaches were adopted by the doctors. We then undertook a detailed de-brief of patients after the event. Working with a small number of purposively selected patient interview transcripts enabled us to examine their responses in depth. This may be a more sensitive methodology to elicit preferences or experiences in this area than other methods which use more fixed responses.<sup>36,37</sup> Patients needed little encouragement to describe their experience in the consultation in detail.

However, some of these features are also potential weaknesses. Being from a small study, the findings require replication elsewhere with different patients to explore the influence of context. Further work should also broaden the focus to explore the relative importance of shared decision-making aspects compared with other more global aspects such as feelings of respect, enablement or other important outcomes of patient-centred consultations.<sup>38</sup> Patients' recollections of decision making may not be consistent with what happens during the consultation itself and using consultation recordings or transcripts as prompts for reflection can yield valuable insights.<sup>7</sup> There may be issues of social desirability in the responses. However, patient perceptions based on recollection of what occurred are at least as important as what actually may have happened<sup>39</sup> and this was our chosen method. Lastly, some interviews were conducted some time after the consultation, and the delay may have altered the views given by patients.

### Context of other literature

Despite significant conceptual and theoretical framework development in the field of shared decision making,<sup>1,27,40–42</sup> relatively little research has observed shared decision making in practice or explored patients' perspectives. We know

much about general health-care communication,<sup>43</sup> and about shared decision making from clinicians' perspectives.<sup>5,22</sup> Some research into decision making identified differences between patient reports and observations<sup>21</sup> and differences between patients' narratives of then events and their responses to commonly used scales for assessing involvement.<sup>9,36,37</sup> Saba *et al.* explored the patient's perspective in more detail, identifying variable patient evaluations of shared decision making in terms of whether it reflected 'genuine', 'false' or 'absent' partnership, and whether it provided a positive experience for the patient or not.<sup>7</sup> Our study, based on patients with a wide range of clinical conditions, is also based on empirical data on the process as perceived by patients. It offers further insights into the practical workings of a theoretically derived model of patient–doctor interaction in routine general practice. There are empirical data about, for example, the effectiveness of decision aids, operating in a context of patient involvement,<sup>44</sup> but these must also be matched to the context and goals for an individual health-care encounter.<sup>25</sup>

When and how to implement shared decision making requires a clear conceptualization. We believe the literature to date, thoroughly reviewed recently,<sup>27</sup> has insufficiently distinguished between the process of involvement and final decisional responsibility. The process includes the competences that ensure patient engagement in discussions – option portrayal, equipoise statements, exchange of information and opinions, clarifying values and exploring preferences for who makes the decision. This process needs to be clearly distinguished from who actually makes the decision ('decisional responsibility' – the classic spectrum from 'paternalism' through 'shared' to 'informed choice' models).<sup>1</sup> We will now explore this further.

### Implications

#### *Theoretical understanding of shared decision making*

Although the doctors probably intended to share decision making, the actual decision was perceived (by patients) as patient-led in as

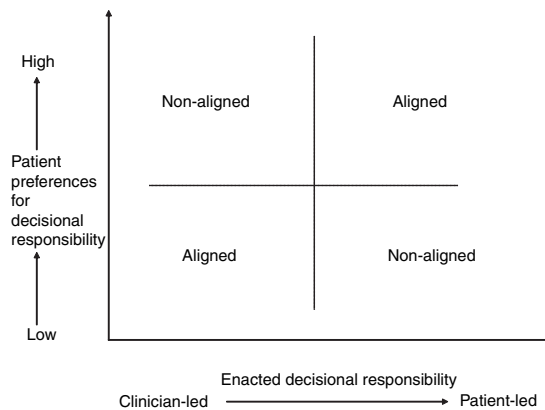
many consultations as those in which it was perceived to be shared. Doctors may have been (often, at least) responding to cues from patients, perhaps their interest and comfort with information and involvement or desires for decisional responsibility, and different consultation approaches ensued. We do not have data about whether the model used (as perceived by the patient) specifically matched their preference for decisional responsibility, but there were few indications of dissatisfaction. Both the shared and informed choice approaches can be viewed under the umbrella of 'shared decision making' as patients were *involved to the extent that they desire*.

#### *Process not outcome*

In contrast to the theoretical importance attached to the locus of decision making in the literature, this appeared a grey area of relatively little importance for patients in the inexact world of general practice consulting. By comparison, patients readily articulated the components of shared decision making – sharing information, assessing risks, reviewing options and relating this knowledge, with their doctor's support, to their own personal situation before leading to a decision. We found that all patients in the study described at least some of these components, while only half the patients described their decision as shared with the doctor. This offers some validation of the competences themselves as achievable and tangible steps in the process,<sup>6</sup> and also supports the hypothesis above that all these models of actual decision making can be viewed under the umbrella of shared decision making. Satisfaction levels were high, regardless of the model experienced. It was the *process* of involvement that appeared to deliver benefits for patients, *not the action* of making the decision.

#### *Alignment of preferences for and actual decisional responsibility*

Our data suggest that there was evidence of changing responsibility for decisions within some consultations: at times the perceived responsibility lay more with the doctor, and at



**Figure 1** Alignment and non-alignment of preferences and enacted decisional responsibility. Alignment is dynamic not fixed and must be reviewed at various stages of the consultation to achieve appropriate and successful shared decision making.

others it may have been shared or patient-led. Non-alignment (see Fig. 1) can occur either when the patient wishes to adopt decisional responsibility but the actual (or 'enacted') decisional responsibility is clinician-led or *vice versa*. Such non-alignment between preferences and actual decisional responsibility appeared detrimental to the process. Unwanted responsibility<sup>45</sup> might be more detrimental than the 'traditional' paternalistic approach, though our data do not examine this. As preferences and actual decisional responsibility appeared to have varied during consultations, clinicians need to be aware of this feature and constantly check for alignment between these dimensions. Given the still unequal power relationships between doctors and patients,<sup>46</sup> the opportunity for patients to come into a decision 'space' remains in the gift or control of clinicians and they must make conscious efforts to *achieve* appropriate involvement. The data here support the framework suggested by Charles *et al.* and indicate that flexibility is needed during a consultation, rather than simply adopting one style, even a shared decision-making one.<sup>40</sup> We hypothesize that involvement in the process and alignment of decisional responsibility with patient preferences are each required for a successful shared decision-making consultation.

### Practice

We suggest successful shared decision making is part of the ongoing doctor–patient dialogue, one in which doctors introduce patients to greater involvement and respond to patient cues for decisional responsibility. Doctors should look to adopt an appropriate level of engagement with patients. Although age and low educational levels may in general predict patients' reluctance to share decisions,<sup>47</sup> doctors have found it hard to predict individual preferences for involvement.<sup>16</sup> Clinicians must keep an open mind about which patients and when to share decisions, and remain open to change even within consultations.

There are often low patient expectations for involvement. However, people's expectations and valuations of involvement increase after experiencing it.<sup>16</sup> The current self-fulfilling prophecy – of no experience and low expectations, matched by clinicians – could be ended by making people more aware of the opportunity for involvement, the time commitment required, and the benefits for patients. The 'pull' from patients is more effective than the 'push' from professional quarters to promote shared decision making.<sup>48</sup>

### Training

However, professional development initiatives are still needed. Shared decision making is promoted mainly in postgraduate training programmes, as this is when clinicians are best able to reflect on how they make clinical decisions.<sup>49</sup> There is debate<sup>24</sup> about whether teaching specific communication skills (competences) will result in a shift in more global attitudes and approaches (competencies). Patients' reports here indicate that they perceived changes in the global process of consultations, noting a new sense of opportunity, involvement and trust. The doctors had been trained in work-based experiential workshops based on the acquiring specific competences.<sup>50</sup> We cannot say from these data that this is more effective than an approach based on global competencies, but it does appear to have enabled doctors to adopt the approaches with actual patients presenting with problems requiring current decision making.

We propose requirements for successful shared decision making which are relevant to training and skill acquisition. The issue of checking for alignment of decision-making desires and model during consultations represents in essence a new competence to integrate with the existing frameworks.<sup>5,6</sup> Some existing competences require more emphasis in training, for example being even clearer with patients about the range of options available – especially the option of 'doing nothing'. This study also highlighted the doctor's role in appraising information for patients. Although doctors struggle with such evidence sources, this competence must remain an integral part of shared decision-making training.

### Further research

Further research should explore whether empirical data from patients in different countries, settings or with different conditions complement the theoretical models in the literature. Similarly, further enquiry with clinicians may deepen understanding further, perhaps particularly to inform the way training programmes are designed. Closer examination of the relationship between patients' perceptions of the process (as reported here) and the actual process (for example by analyses of the consultation discourses) could further illuminate the understanding of decision-making models.

### Conclusion

It is important to distinguish between the process of involvement and decisional responsibility itself. Patients in this study were aware of and benefited from the *process* of shared decision making, regardless of *who* they believe made the treatment decision. There may be differences between patient preferences for and actual decisional responsibility in the consultation. Patient satisfaction levels were only low with clear non-alignment between patient preferences for and actual decisional responsibility. Such alignment or not may change during a consultation, so clinicians need to check this repeatedly to achieve successful shared decision making.

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